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PERSONAL ASSISTANT SERVICES AGING AND PHYSICAL DISABILITIES MODULE

SECTION I - OVERVIEW

I. Overview

- A. Services and continuum of care
- B. Independent living
- C. Roles and responsibilities of DSP
 - 1. Training
 - 2. Scope of Practice
- D. Ethical Principles



A. Services and continuum of care

The **individual's home** (or a relative's home)

--Individual may also attend adult day services or school

A group home

--Usually for a specific group of disabilities such as a group home for individuals with developmental disabilities

An assisted living home

- --Provides 24 hour care in a home-like setting for 1-10 residents
- -- May or may not be owner occupied
- --An adult foster care home is owner occupied and cares for 1-4 residents

An assisted living facility

- --Consumers usually live in individual apartments and pay for the services they use
- --Larger facilities, can be up to 100 or more units
- --Often the larger facilities are divided into functional units depending on how much help the consumer needs

A dementia specific unit

- --Similar to an assisted living facility but is specific to the care of consumers who have dementia
- --These units are usually locked so that consumers cannot wander away

A skilled nursing facility ("nursing home")

--Skilled nursing care 24/7

B. Independent living

In the Independent Living philosophy, people with disabilities are <u>primarily seen as</u> <u>citizens</u> and only secondarily as consumers of healthcare or social services.

As emphasized by the IL Movement, needs assessment and service delivery must enable users to control their services, to freely choose among competing service providers and to live with dignity in the community.

Benefits:

- a. Offers freedom of choice
- b. Increases independence and feelings of self worth
- c. Promotes health and socialization

From Wikipedia, the free encyclopedia: http://en.wikipedia.org/wiki/Independent living

C. Roles and responsibilities of DSP

1. Training

a. Orientation

Once a DSP is hired by an agency, he/she will be required to attend the agency's orientation even though the individual completed this course. The orientation to the agency is much more specific to the particular agency such as policies, paperwork requirements, history, job expectations, etc.

b. Continuing education units (CEUs)

Professional standards dictate the importance of continuing education to keep abreast of changes in the field. The DSP may be required to obtain CEUs for the service provided. This also expands the DSP's training and skill level to improve the delivery of quality care.

2. Scope of practice

Scope of practice refers to what an employee is allowed to do and not do on the job. The scope may change according to the type of setting the DSP works in. However, <u>all</u> DSPs have professional standards to adhere to.

a. DSP Professional Standards

- Maintain high standard of personal health and hygiene and appearance.
- Be dependable and reliable.
- Carry out responsibilities of the job the best way you can—take pride in a job well done.
- Show respect for each consumer's privacy.
- Recognize and respect the right of self-determination and lifestyle.
- Keep professional life separate from personal life.
- Control any negative reactions to chronic disability or living conditions.
- Maintain safe conditions in the work environment.
- Do not use the consumer's medications for your own health problems.
- Do not give your cell number or home number to your consumer.

D. Ethical principles

- a. Confidentiality: do not discuss confidential information with others except your supervisor or other colleagues that are directly involved with the consumer's care. Confidential information may include medical, financial or family issues.
- b. **Honesty**: do not be afraid to politely say "no" to a task you are not assigned to do. Also, do not be afraid to admit that you do not know the answer to a question or how to do a task. Never steal, take a consumer's possessions, or falsify documents or reports.
- c. **Respect**: a consumer's religious or personal beliefs and values. They will possibly differ from yours and you should respect those differences.
- d. **Reliability**: arrive for assignments on time. Always finish your shift, even if a consumer is being difficult or the workload is too difficult. You can address those problems with the supervisor after you have finished your shift.
- e. You should not take gifts or tips.
- f. If you discover a case of abuse, report it to your supervisor as soon as practical.
- g. Never have sexual relations with a consumer.
- h. Do not change the consumer's care plan without contacting your supervisor first.

A DSP should check with his/her Supervisor to get clarification as to expectations and responsibilities.

It is <u>ALWAYS</u> better to ask questions than to do something that may be unsafe, cause for disciplinary action, and/or a liability issue.

PERSONAL ASSISTANT SERVICES AGING AND PHYSICAL DISABILITIES MODULE

SECTION II - LEGAL AND ETHICAL ISSUES

II. Legal and Ethical Issues

A. Overview

- 1. Review of definitions
- 2. Avoiding legal action
- 3. Consumer rights and dignity
- 4. DSP rights
- 5. Confidentiality



A. Overview

1. Review of definitions

- a. **Abandonment** is when a family or agency leaves an individual in a potentially dangerous situation without care or support.
- b. **Assault** occurs when an individual intentionally attempts or threatens a harmful or offensive touching of another individual without their consent.
- c. **Battery** occurs when an individual harmfully or offensively touches another individual without their consent.
- d. **False imprisonment** occurs when you restrict an individual's freedom to leave a place when they choose to do so unless restraint is necessary for safety and to avoid harm.
- e. **Invasion of privacy** is revealing personal or private information without an individual's consent.
- f. **Liability** refers to the degree to which you or your employer will be held financially responsible for damages resulting from your negligence.
- g. **Malpractice** is a failure to use reasonable judgment when applying your professional knowledge and skills.
- h. **Negligence** is when a personal injury or property damage is caused by your act or your failure to act.

2. Avoiding legal action

- a. Keep personal information confidential: Do not discuss confidential information with others except your supervisor or other colleagues that are directly involved with the consumer's care. Confidential information may include medical, financial, or family issues.
- b. **Only perform work assigned**. If you perform a task that was not assigned by your supervisor, you become liable for those actions.
- c. **Do not do less work than assigned**: When you fail or forget to do all the tasks assigned, you may put your consumer at risk. As a result of your failure to act, you might be found negligent.
- d. **Avoid doing careless or low-quality work**: Performing tasks carelessly might make you liable for the damages or injuries that result.

3. Consumer rights and dignity

- a. Considerate and respectful treatment and care.
- b. Not to be abused emotionally, sexually, financially, and/or physically
- c. Treatment or care plan designed so he/she can decide how services will be provided and who will deliver those services (including requesting a change of caregiver)
- d. Receipts or statements for their fee-based service
- e. Refuse treatment
- f. File a complaint with the agency
- g. Privacy and confidential handling of their personal information

4. DSP rights

- a. File a complaint without the fear of retaliation
- b. Not to be abused emotionally, sexually, financially, and/or physically.
- c. Suggest changes to a consumer's care plan in order to make delivery of care more efficient and less stressful
- d. Be informed when a consumer files a complaint against you
- e. A confidential investigation, a fair hearing, and the outcome when addressing complaints against you
- f. Receive timely payment for your services including salary and mileage
- g. Work in a safe environment

5. Confidentiality

(Refer to HIPAA Section in the Core Training)

All information about our consumers is considered private or "confidential" whether written on paper, saved on a computer, or spoken aloud. This includes their name, address, age, Social Security number, medical conditions and any other personal information. It also includes the reason the consumer is sick, the treatments and medications he/she receives, caregiver information, any information about past health conditions, future health plans, and why the consumer is open to services.

Spoken communication runs the gamut from conducting consumer interviews, paging consumers, whispering in corridors, to talking on telephones. Written communication includes the hard copy of the medical record, letters, forms, or any paper exchange of information. Electronic communication includes computerized medical records, electronic billing and e-mail.

If you reveal any of this information to someone who does not "need to know" it, you have violated a consumer's confidentiality, and you have broken the law.



II. Legal and Ethical Issues (cont'd)

B. Vulnerable adult abuse

- 1. Definitions and examples
- 2. Indicators
- 3. Causes
- 4. Prevention
- 5. Reporting requirements
- 6. Legal penalties
- 7. Other



B. Vulnerable adult abuse

1. Definitions and examples

Adult abuse refers to any form of maltreatment of a person by a caregiver, family member, spouse, or friend. Categories of abuse include:

Abuse

Intentional infliction of physical harm, unreasonable confinement, or sexual abuse or sexual assault (sexual contact with any person incapable of giving consent)

Neglect

Failing to provide a person food, water, clothing, medicine, medical services, shelter, cooling, heating or other services necessary to maintain minimum physical or mental health

Financial exploitation

The improper use of a person's funds, property, or assets. This includes forgery, stealing money or possessions, or tricking a person into signing documents that transfer funds, property, or assets.

Emotional abuse

Psychological abuse such as name-calling, insults, threats, and intimidation

2. Indicators/Signs

- a. Physical: bruises, broken bones, cuts or other untreated injuries in various stages of healing.
- b. Sexual: bruises around breast or genital areas; signs of sexually transmitted diseases (STDs).
- c. Emotional: adult is upset or agitated, withdrawn, non-communicative, or paranoid.
- d. Neglect: dehydration, malnutrition, pressure ulcers, poor personal hygiene, and unsafe or unsanitary living conditions.
- e. Financial: unusual banking activity; missing financial statements or other personal effects such as jewelry; signatures on checks that do not match adult's signature.

3. Causes/profile of the abuser

- a. Often a family member
- b. Caregiver is ill-prepared to provide care
- c. Ineffective coping pattern/stressed caregiver
- d. Life is in disarray
- e. Financial problems
- f. Substance abuser
- g. Marital conflict and/or history of violence in the family
- h. Financial dependency on the vulnerable adult by the abuser
- i. Mental illness and/or alcohol/drug addition
- j. Abuser isolates adult to prevent the abuse from being discovered

4. Prevention

- a. Community awareness
- b. Public and professional education
- c. Caregiver support groups
- d. Stress management training
- e. Respite care
- f. In-home services

How can you help?

- a. Be aware of the causes and closely monitor vulnerable adults at higher risk
- b. Help adult maintain close ties with family or friends
- Recommend organizations or resources that provide elder abuse prevention services or assist victims of abuse
 - Arizona Attorney General's Office, Elder Affairs Program, 602-542-2124, www.ag.state.az.us
 - Arizona Department of Health Services, 602-364-2536, www.ha.state.az.us

5. Reporting requirements (Mandatory reporting)

- a. All persons who are responsible for the care of an incapacitated or vulnerable adult **have a duty to report** suspected abuse and neglect.
- b. Reports must be made immediately (by phone or in person) to a peace officer or a protective service agent. **Failure to report is a misdemeanor.**
 - If the adult is in immediate danger, call 911.
 - If the abuse is not life-threatening, report it to your Supervisor who will assist you in making the report to:
 - ✓ Adult Protective Services: 1-877-SOS-ADULT; this is a 24-hour a day statewide reporting line; www.de.state.az.us/aaa/apsciu/default.asp
 - ✓ Area Agency on Aging: 602-264-HELP, www.aaaphx.org
 - ✓ Department of Health Services: 602-674-4200. This line is available Monday through Friday, 8:00 a.m.-5:00 p.m.

Immunity (ARS 46-453)

All persons reporting are immune from any civil or criminal liability so long as the report does not involve any malicious misrepresentation.

6. Legal penalties

ARS 46-455 states that:

Any person who has been employed to provide care to an incapacitated or vulnerable adult and who causes or permits the person's life to be endangered or his/her health to be injured or endangered by neglect can be found guilty of a felony.

An individual who is found guilty of a felony will not only face jail time but a felony conviction also limits the type of jobs the individual can hold in the future (i.e. convicted felons are unable to work in most healthcare or educational systems).

7. Other

A good reference on Elder Abuse is a booklet that is distributed by the Area Agency on Aging, Region One. You may obtain free copies by contacting their office.

PERSONAL ASSISTANT SERVICES AGING AND PHYSICAL DISABILITIES MODULE

SECTION III - SUPPORT/CARE PLANS

III. Support/Care Plans

- A. Development
- B. Importance of following support/care plans
- C. Documentation and reporting



A. Development

- 1. A care or support plan (depending on the agency terminology) is a written plan created to meet the needs of the consumer.
- 2. The plan is usually created during an in-home assessment of the consumer's situation and the abilities and care being provided by family and friends.
- 3. The plan defines the needs and objectives/goals for care.
- 4. The plan lists the tasks to be provided by the DSP.
- 5. Care/support plans are reviewed by the care team. The DSP might be asked for input as to how the plan is working. Reporting and documenting are critical in evaluating whether the plan is working or if it needs revision.

B. Importance of following support/care plans

Any deviations from a care or support plan may put the DSP at risk for disciplinary action. Therefore, any changes need to be approved by the supervisor.

C. Documentation and reporting

The purpose of observing, reporting, and documenting is to communicate any changes that may be occurring with the consumer and/or family. This can be accomplished by **observing** and monitoring changes and **reporting** and **documenting** those changes.

Documentation Guidelines:

- a. Always use ink.
- b. Sign all entries with your name and title, if any, and the date and time.
- c. Make sure writing is legible and neat.
- d. Use correct spelling, grammar, punctuation and abbreviations (Refer to the Standardized Medical Abbreviations list on the following pages).
- e. Never erase or use correction fluid. If you make an error, cross out the incorrect part with one line, write "error" over it, initial it, and rewrite that part.
- f. Do not skip lines. Draw a line through the blank space of a partially completed line or to the end of a page. This prevents others from recording in a space with your signature.
- g. Be accurate concise, and factual. Do not record judgments or interpretations.
- h. Make entries in a logical and sequential manner.

- i. Be descriptive. Avoid terms that have more than one meaning.
- j. Document any changes in the consumer's condition. Also document that you informed the consumer's physician or your supervisor as indicated.
- k. Do not omit any information.
- I. Try to relate your charting to the objectives/goals on the consumer's plan, (i.e., if a goal is "walking", document "walked 3 times today without assistance from bedroom to kitchen" instead of "had a good day today").

Activity:

1. Mabel, who has Alzheimer's disease is being cared for by her son. The care plan states that you are to help Mabel with a bath and assist with preparing meals. When you arrive at Mabel's home, Mabel asks you to drive her (you can use Mabel's car) to the grocery store to pick up something for lunch.

What would your actions be and what would your charting look like in this case?

2. You are to provide bathing assistance for Mabel. When you arrive at her house at the scheduled time, you notice that she has an imprint of what looks like a hand on her right cheek. Mabel states that she must have fallen asleep with her hand on top of her pillow.

What would your actions be and what would your charting look like in this case?

PERSONAL ASSISTANT SERVICES AGING AND PHYSICAL DISABILITIES MODULE

SECTION IV - BIOLOGICAL ASPECTS OF AGING



- A. Heart and lungs
 - 1. Biological changes
 - 2. Implications for care



- 1. Biological changes
- 2. Implications for care



Biological Aspects of Aging (Refer to chart on the next page)

A. Heart and lungs

1. Biological changes

- a. Heart does not pump as efficiently (pump begins to "poop out")
- b. Lungs do not exchange oxygen and carbon dioxide as efficiently
- c. Not as much oxygen delivered to all parts of the body
- d. Decreased blood flow to all parts of the body

2. Implications for care

- a. Rest before changing positions to prevent fainting
- b. Allow more time (don't rush) for ADLs including walking, bathing, dressing

B. Kidneys and bladder

1. Biological changes

- a. Decreased function of the kidneys not as able to filter medication by-products
- b. Decreased bladder capacity (2 cups at age 25; 1 cup as an elder)
- c. Decreased signal time for urge to urinate; may urinate as urge signal received leading to incontinence
- d. Increased incidence of stress incontinence and urinary retention (increased bladder/kidney infections)
- e. Prostate gland increases in size

2. Implications for care

- a. Monitor for toxic medication reactions
- b. Prevent incontinence with routine toileting every two hours, use easy to remove clothing, and use a bedside commode as indicated
- c. Monitor for signs of bladder/kidney infections (change in behavior, temp, etc.)
- d. Monitor for signs of skin breakdown

Changes As We Age And Implications For Care

	Physical Change with Aging	Implications for Care
Heart and Lungs	 ↓cardiac and lung function 	 Allow more time for ADL's including walking, bathing,
	↓blood flow	dressing
	 Not as much oxygen delivered to all parts of the body 	Rest before changing positions to prevent fainting
Kidneys,	 ↓ function of kidneys; med toxicity 	Be aware of medication side effects
Bladder	↓bladder capacity: 2 C @25; 1 C elder	Prevent incontinence; regular toileting, easy to remove
	• ↓ signal time for urge to urinate; may urinate as	clothing, use bedside commode
	urge signal received causing incontinence	Watch for sign of bladder/kidney infections (change in
	↑ incidence of stress incontinence & urinary	behavior, low grade fever, frequent/painful urination)
	retention → bladder/kidney infections	Watch for signs of skin breakdown
Muscles, Bones,	↑ size of prostate gland in men— BPH	Description of the second seco
Tendons and	Loss of muscle tone; joints less flexible	 Prevent falls by clearing pathways and removing scatter rugs
Ligaments	 Osteoporosis-bones less dense, more brittle with increased risk of fractures 	Avoid rushing elder when walking
	 Cartilage between vertebra shrinks →shorter, 	Encourage use of hand rails and/or assistive devices for
	stooped posture	support
	 Slower reflexes and coordination→ falls 	
Nervous and	 Sleep pattern changes, ↑ wakening 	Encourage quiet mental stimulation or light snack during
Immune System	 Nerves react more slowly; less sensitive to pain and 	wakeful periods at night
	temperature extremes,	Check skin, especially feet for cuts, bruises, burns
	↓ sensitivity to pain; injuries may go undetected	 Watch for signs of infection: fever, ↓ appetite, poor color,
Dunin	 ↓ability to fight infections 	change in behavior
Brain, Intelligence, and	Loss of brain cells, learning takes longer	Reduce stress of learning new things, keep environment calm and routine
Memory	Takes longer for brain to search and retrieve	Present new things visually and verbally
	 Intellect, judgment, comprehension, and retention usually do not change with age 	Notify Supervisor of sudden change in memory
Vision	I visual acuity, difficult to read and judge distance	Provide adequate lighting day and night
	• ↑ sensitivity to glare	Reduce glare (mirrors, high gloss furniture, etc.)
	Changes in lens of the eye (cataracts)	Use contrasting colors for floors, walls, steps
	• ↑ risk of glaucoma	Use eyeglasses and keep them clean
		Arrange for annual eye exams
Hearing		Speak clearly but don't shout
	hear if they can not see speaker or with background	Face person, remove anything from mouth (gum, food)
	noise	Encourage use of hearing aids; clean w/ soft brush; have
	May withdraw or get depressed	good batteries available
D'a a Cara	Earwax buildup easily overlooked	Have Health Care Provider examine ears
Digestion, Taste, Smell,	 ↓ gastric acid and saliva enzyme production 	Avoid foods that are difficult to digest or chew
Mouth and	 Slowed peristalsis can lead to indigestion, 	• For constipation: ↑ fluid intake, fresh fruit, veggies, whole
Teeth	constipationLoss of teeth; person doesn't chew food as well	grains, prunes, exercise
	 Sense of taste & smell, food may not taste the 	 Add appropriate herbs, spices, and have pleasant eating environment
	same leading to poor appetite and malnutrition	Important to keep record of how much consumer is eating or
	3 1 11	if skipping food
Skin, Hair and	Skin is drier, less elastic, more fragile; bruises and	Use lanolin based soaps; ↓ use of antibacterial or deodorant
Fingernails	tears more easily	soaps or alcohol based products
	 Fatty layer decreases (↓ natural padding) 	Watch for signs of skin breakdown
	• †facial hair in women (may need trimming)	Frequent change of positions
	 Nails thicken and become more brittle 	File nails, Do Not Clip



- C. Muscles, bones, tendons, and ligaments
 - 1. Biological changes
 - 2. Implications for care



- D. Nervous and immune systems
 - 1. Biological changes
 - 2. Implications for care



C. Muscles, bones, tendons, and ligaments

1. Biological changes

- a. Loss of muscle tone; joints become less flexible
- b. Bones become more porous, more brittle with increased risk of fractures
- c. Cartilage between vertebrae shrinks making the person shorter with stooped posture
- d. Slower reflexes and coordination increases risks for falls

2. Implications for care

- a. Prevent falls by removing barriers and scatter rugs and clearing pathways
- b. Avoid rushing the elderly person when walking
- c. Encourage use of hand rails and/or assistive devices for support
- d. Ensure adequate lighting especially at night

D. Nervous and immune system

1. Biological changes

- a. Sleep pattern changes, increased waking during the night
- b. Nerves react more slowly; less sensitive to pain and temperature extremes
- c. Decreased sensitivity to pain; injuries may go undetected
- d. Decreased ability to fight infections

2. Implications for care

- a. Encourage quiet mental stimulation or light snack during wakeful periods at night
- b. Check skin for any signs of breakdown
- c. Check feet and between toes for cuts, bruises, burns or lesions
- Watch for signs of infection: change in behavior, fever, decreased appetite, poor color



IV. Biological Aspects of Aging

- E. Brain, intelligence, and memory
 - 1. Biological changes
 - 2. Implications for care



F. Vision

- 1. Biological changes
- 2. Implications for care



E. Brain, intelligence, and memory

1. Biological changes

- a. Loss of brain cells, learning takes longer
- b. Takes longer for brain to "search and retrieve"
- c. Intellect, judgment, comprehension, retention usually do not change with age

2. Implications for care

- a. Reduce stress of learning new things, keep environment calm and routine
- b. Present new things visually and verbally
- c. Notify Supervisor of sudden change in memory

F. Vision

1. Biological changes

- a. Decreased visual acuity, difficult to read and judge distance
- b. Increased sensitivity to glare
- c. Changes in lens of the eye (cataracts)
- d. Risk of increasing fluid pressure within the eye (glaucoma)

2. Implications for care

- a. Provide adequate lighting day and night
- b. Reduce glare (mirrors, high gloss furniture, etc.)
- c. Use contrasting colors for floors, walls, steps
- d. Use eyeglasses and keep them clean
- e. Arrange for annual eye exams



- G. Hearing
 - 1. Biological changes
 - 2. Implications for care



- H. Digestion, taste, smell, mouth, and teeth
 - 1. Biological changes
 - 2. Implications for care



G. Hearing

1. Biological changes

- a. Decreased hearing
 - High frequency sounds distorted
 - Difficult to hear if they cannot see speaker
 - May withdraw or get depressed due to not being able to join in conversations
 - Increased earwax buildup can easily be overlooked

2. Implications for care

- Speak clearly but don't shout; reduce background noise (turn off TV and radio, etc.)
- b. Face person when talking, remove anything from mouth (gum, food)
- c. Encourage use of hearing aids (clean aids with soft brush; have extra batteries)
- d. Have health care provider examine ears

H. Digestion, taste, smell, mouth, and teeth

1. Biological changes

- a. Decreased gastric acid and saliva enzyme production
- b. Slowed peristalsis can lead to indigestion, constipation
- c. Loss of teeth; affects chewing food
- d. Decreased sense of taste and smell; food may not taste the same

2. Implications for care

- a. Avoid foods that are difficult to digest or chew
- b. For constipation: increase fluid intake, fresh fruit, veggies, whole grains, prunes, and exercise
- To encourage intake add appropriate seasonings and have pleasant eating environment
- d. Important to keep record of person's weight, appetite, and bowel regularity

Discuss use of personal amplifier as alternative to hearing aids



- I. Skin, Hair and Fingernails
 - 1. Biological changes
 - 2. Implications for care



I. Skin, Hair and Fingernails

1. Biological changes

- a. Skin is drier, less elastic, more fragile; bruises and tears more easily
- b. Fatty layer decreases (decreased natural padding)
- c. Increased facial hair in women (may need trimming)
- d. Nails thicken and become more brittle

2. Implications for care

a. GOAL IS TO KEEP SKIN INTACT

- b. Use lanolin based soaps instead of antibacterial or deodorant soaps or alcohol-based products
- c. Inspect the person's skin for signs of skin breakdown frequently
- d. Use lotion to help keep the person's skin supple and relieve dry, scaly skin
- e. Change the person's position in bed or chair at least every two hours to relieve pressure
- f. File nails, **Do Not Clip**

A Tip: To relieve extreme dryness of the hands and/or feet apply petroleum jelly to the area and cover with cotton gloves or socks before going to bed.

Refer to other skin care strategies and information on pressure ulcers found in the personal care section of the Core Training

PERSONAL ASSISTANT SERVICES AGING AND PHYSICAL DISABILITIES MODULE

SECTION V - ACUTE AND CHRONIC CONDITIONS



V. Acute and Chronic Conditions

- A. Therapeutic interventions
- B. Acute versus chronic illnesses
 - 1. Differences
 - 2. Joints and bones
 - a. Arthritis
 - b. Osteoporosis



A. Therapeutic interventions

Therapeutic interventions are care strategies and treatments given based on individual diagnosis and needs and addressed in the care/support plan.

B. Acute versus chronic illnesses

1. Differences

- a. Acute illnesses progress rapidly, last a certain length of time, and then the person recovers
- b. Chronic illnesses are long-term conditions requiring prolonged care. According to the U.S. National Center for Health Statistics a chronic illness lasts three months or more.

2. Joints and bones

- a. Arthritis—Causes inflammation and deterioration of the joints. There are two main types:
 - Osteoarthritis
 - ✓ Degeneration of the joints causing pain and stiffness
 - ✓ Most common form of arthritis—90% of people over 50 have some osteoarthritis _______
 - ✓ Symptomatic treatment is aspirin or non-steroidal antiinflammatory drugs (i.e., Ibuprofen, Naproxen)
 - Rheumatoid Arthritis (RA)
 - ✓ More severe form but less common
 - ✓ Causes joint deformities
 - ✓ More difficult to treat since it is considered an autoimmune disease (immune system turns against itself)
 - Can also affect internal organs such as heart lungs and muscles

Discuss implications that non- verbal elders with certain conditions (i.e. dementia) may have problem behaviors due to arthritis pain and not be able to tell you.

- b. Osteoporosis--Loss of calcium in the bones making them porous and brittle with increased risk of fractures
 - Risk factors- hereditary factors, decreased calcium intake, lack of exercise
 - Treatments aimed at meds to increase calcium uptake and weight training (exercising with weights helps calcium re-absorption)
 - Causes shortened stature as the vertebrae collapse and the spine curves leading to decreased range of motion and painful mobility
 - Causes compression fractures of the spine
 - Fractures increase risk of joint replacement surgery
 - ✓ Major surgery can cause complications in elderly persons
 - ✓ Majority of elders who have hip replacement surgery never return to independent functioning



V. Acute and Chronic Conditions

- 3. Heart
 - a. High blood pressure
 - b. Cardiovascular disease
 - c. Angina
 - d. Heart attack (myocardial infarction)
- 4. Lungs
 - a. Emphysema
 - b. Asthma



3. Heart

a. High blood pressure/hypertension (HBP, HTN)

High blood pressure affects almost 30% of adults in the U.S., yet most of these people have no symptoms. Uncontrolled high blood pressure can lead to stroke, heart attack, heart failure or kidney failure. The only way to tell if a person's blood pressure is within the normal range is to have it checked regularly.

Blood pressure guidelines are:

The target BP should be	Less Than 140/90		
If the person has diabetes or kidney	Less than 130/80		
problems the target BP should be			
When to notify the Health Care Provider			
Systolic (top number)	Less than 90		
	Greater than 160		
Diastolic (bottom number)	Less than 60		
	Greater than 90		

b. Cardiovascular disease--involves the heart and/or blood vessels (arteries and veins)

This disease usually refers to plaque formation on the internal walls of the vessels, namely the coronary arteries. The plaques (atherosclerosis) can totally obstruct the passage of blood causing pain (angina) and death of the affected heart muscle (myocardial infarction).

c. Angina (See above)

Angina is chest pain due to the lack of blood (oxygen supply) to the heart muscle generally due to obstruction of the coronary arteries. Some individuals have known blockages but are not good surgical candidates for coronary artery bypass surgery. Therefore, medications to dilate blood vessels are prescribed. Nitroglycerin (NTG) is such a drug. When the person feels chest pain (can also be pain radiating down arm or jaw) he/she should rest, and take NTG if prescribed. Usual prescription dosing means the person should take one NTG pill under the tongue and wait 5 minutes. If the pain persists, the person can repeat the sequence twice.

Note: If you assist someone in taking a NTG pill, always put the pill in the bottle cap, not in the palm of your hand, as the pill can dissolve in the sweat on your hand giving you the side effects of the med (severe, pounding headache). Also, the person needs to get a fresh supply of NTG tablets every six months as the pills are destroyed by light.

d. Heart attack (myocardial infarction, "MI")

The heart muscle that does not get the needed blood (oxygen) dies. The extent of the affected muscle determines the functional impairment the individual will have following the MI. Cardiac rehabilitation, aimed at progressive exercise, will help the person regain strength and learn how to avoid future attacks through proper diet and exercise.

4. Lungs—Chronic Obstructive Pulmonary Disease (COPD)

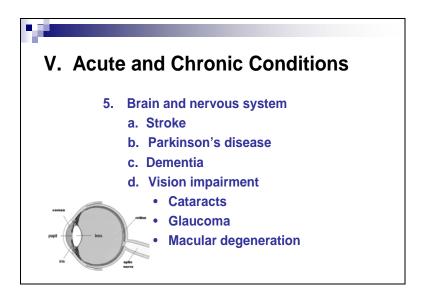
Includes chronic bronchitis, asthma, and emphysema

a. Emphysema

- Breathing is difficult due to swollen, inflamed air passages, damaged air sacs (alveoli) in the lungs, excess mucous, and anxiety
- Treatment includes medications, quitting smoking, staying as active as possible, and oxygen therapy
 - ✓ Oxygen precautions include:
 - Keep tubing away from any heat source including cigarettes and space heaters
 - Store E-tanks upright but secure so they cannot be bumped into or fall over
 - When traveling make sure the E-tanks are secured in the car (use a bungee cord and strap to the back of the passenger seat)

b. Asthma

The individual is hyper-sensitive to certain things such as allergies, viral infections, cold air, exercise, smoke, etc. When exposed to one of these (a flare-up or exacerbation) the person's air passages become swollen and restrict air movement. Immediate medical attention/medications (including the use of inhalers) is indicated or the condition could lead to respiratory arrest and even death.



5. Brain and nervous system

a. Stroke (Cerebrovascular Accident—CVA)

Brain damage occurs when blood flow to or within the brain is interrupted. Without the oxygen in the blood the brain cells die. The location of those damaged cells will determine the symptoms and severity of the stroke.

Signs and symptoms of a stroke include drooping of one side of the face, slurred speech, visual disturbances, incoordination or paralysis of extremities.

There are two types of strokes:

- Hemorrhagic:
 - When a blood vessel breaks and leaks blood into the surrounding tissue. Can be caused by a weakened artery wall (aneurysm) or by trauma
- Ischemic:
 Interruption of blood flow due to a clot or plaque formation

If the cause is ischemic a medication can be given within the first three hours (per AHA guidelines) that will greatly reduce the effects of the stroke. If the cause is hemorrhagic the same medication can cause further bleeding and possibly death. Therefore, it is imperative the individual be evaluated in the emergency room for the appropriate treatment within two hours of onset of symptoms.

Possible effects of a stroke:

Paralysis Depression

Memory loss Emotional instability

Impaired judgment Seizures

Aphasia (difficulty expressing oneself)

It is also imperative following a stroke that the individual get rehabilitative therapy ASAP to decrease impairment and learn how to manage ADLs with the impairment. The caregiver can also help by allowing the person to be as independent as possible and to allow plenty of time for independent function. This will help decrease depression.

b. Parkinson's disease

- Caused by a chemical imbalance (decreased levodopa) in the brain causing rigidity in movements (freezing), tremors, and loss of facial movements (blank affect)
- Can lead to dementia
- Do not mistake blank affect for lack of comprehension

c. Dementia

Covered later in the Dementia-Specific Care section

d. Vision impairment

- Cataracts
 - ✓ Cloudiness of the lens of the eye leading to decreased night vision, glare, and blurry vision
 - ✓ Current treatment includes out-patient laser surgery
 - ✓ Post-op care includes multiple eye meds and restrictions on lifting and bending over

Glaucoma

- ✓ Fluid pressure builds up inside the eyeball causing pressure on the optic nerve leading to blindness. Damage is irreversible
- ✓ Usually the person does not feel any pressure so it can only be diagnosed with an eye exam
- ✓ Treatment includes eye drops and sometimes surgery
- ✓ Annual eye exams over age 40 are important

Macular degeneration

- ✓ Leading cause of blindness in people over 50
- ✓ The macula (an area of the retina) begins to deteriorate causing blurry or spotty central vision



V. Acute and Chronic Conditions

- 6. Diabetes
 - a. Hypoglycemia
 - b. Hyperglycemia



- 7. Urinary system
 - a. Urinary tract infections (UTI)





6. Diabetes

Diabetes is an imbalance in glucose and insulin in the blood. Insulin is produced by the pancreas and is responsible for transporting glucose molecules in the blood into the cells. **Normal range for fasting blood glucose is 90 to 110**. There are two main types of diabetes:

a. Type I (Early onset/Insulin dependent)

- Pancreas no longer produces insulin (possibly an auto immune disorder)
- Individual must have insulin injections

b. Type II (Late onset/Diet controlled)

- Due to deficiency in insulin production cells become resistant to insulin
- Previously generally only a condition affecting older adults. Now being seen in teenagers
- Possible causes: heredity and diet high in fat and sugar

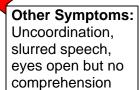
Treatment:

- Diet—can also control "borderline diabetes" (blood sugars just slightly elevated)currently, diet focuses more on amount of carbohydrates consumed at each meal rather than limiting concentrated sweets (allows more food choices)
- Exercise—exercise reduces blood glucose so diabetics are encouraged to be as active as possible
- Oral medications aimed at increasing insulin production or decreasing the cell's resistance to insulin
- Insulin there are different types and lengths of action—now available in powder form that is inhaled

Diabetic complications (what can happen if blood sugars are not controlled)

Blindness	Kidney damage and failure
Poor circulation increasing risk for	Nerve damage in extremities
amputations, heart attacks, and strokes	(diabetic neuropathy)

MEANS A MORE COMMON SYMPTOM(S)







HYPOGLYCEMIA

(Low Blood Glucose)

Causes: Too little food, too much

insulin or diabetes medicine.

or extra activity.

Onset: Sudden, may progress to

insulin shock.





SHAKING

HEARTBEAT





SWEATING



DIZZINESS



ANXIOUS



HUNGER



IMPAIRED VISION



WEAKNESS FATIGUE

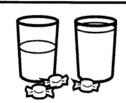


HEADACHE



IRRITABLE





Drink 1/2 glass of juice or regular soft drink, or 1 glass of milk, or eat some soft candies (not chocolate).

Within 30 minutes after treatment **TEST BLOOD GLUCOSE.** If symptoms don't stop, call



Then, eat a light snack (1/2 peanut butter or meat sandwich and 1/2 glass of milk).

vary with different medications.

Concept developed by Rhoda Rogers, RN, BSN, CDE, Sunrise Community Health Center, Greeley, Colorado

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TIP: If a person cannot be trusted to swallow, cake decorating frosting from a tube can be squirted inside the person's mouth and allowed to dissolve.

your doctor

Note: These are also the symptoms for undiagnosed diabetes





(High Blood Glucose)

Too much food, too little insulin or Causes:

diabetes medicine, illness or stress.

Onset: Gradual, may progress to diabetic coma.



SYMPTOMS



FREQUENT URINATION



BLURRED VISION



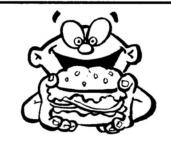
DRY SKIN



DROWSINESS



EXTREME THIRST



HUNGER



DECREASED HEALING



TEST BLOOD GLUCOSE



If over 200 mg/dL for several tests or for 2 days

CALL YOUR DOCTOR

Concept developed by Rhoda Rogers, RN, BSN, CDE, Sunrise Community Health Center, Greeley, Colorado ©Novo Nordisk Pharmaceuticals, Inc. 000-114 1998 Printed in U.S.A.

Diabetic Emergencies – Remember, normal blood sugar is about 90 to 110.

Hyperglycemia range is anything above 125 to 500+ so there is a broad range for high blood sugar and the person can still function.

Hypoglycemic symptoms occur with most people at about 70 so the sugar level just needs to drop a little for the person to start having symptoms. This is because the brain is more sensitive to a drop in blood sugar and will lose function if level is too low.

Therefore, low blood sugars are much more of a danger than high blood sugars. If the person starts to exhibit symptoms of low blood sugar, give the person ½ glass of orange juice or soda followed by a high protein snack such as milk and crackers or half a meat sandwich.

If you give sugar and the person's symptoms do not go away, you know that something else (such as a stroke) could be causing the symptoms. It will **not hurt** the person to be given the extra sugar if low blood sugar is not the cause of the symptoms since high blood sugar has a broad range of sugar levels.

Also, **INSULIN AND FOOD MUST GO TOGETHER**. If the person has their shot and no food you are asking for a diabetic emergency!!!

7. Urinary System

a. Urinary tract infections (UTI) -- usually refers to a bladder infection

Symptoms:

- Urine cloudy and foul smelling
- Low grade fever
- Burning sensation during urination
- Decreased mental acuity (more common symptom in the elderly)

Prevent UTIs with increased fluid intake

b. Benign prostatic hyperplasia (BPH) – an enlarged prostate

The prostate enlarges as a man ages. Most of the time this enlargement is benign (non-cancerous) but it can become cancerous. Cancer of the prostate is the second leading cause of cancer-related deaths in men (lung cancer is first). Therefore, it is very important that men have prostate exams especially if symptoms are noted.

Symptoms:

- Difficulty starting and keeping urine flowing
- Dribbling of urine
- Needing to urinate frequently, more bothersome at night
- History of UTIs due to retained urine

Treatment may include a TURP (transurethral resection of the prostate) in which pieces of the prostate are removed surgically. Post-op care will include pushing fluids and monitoring for increased bleeding into the urine.



- 8. Stomach and colon
 - a. Ulcers
 - b. Constipation/impaction/ obstruction
- 9. Immune system
 - a. HIV/AIDS
 - b. Other



8. Stomach and colon

- a. **Ulcers**
 - Can be in stomach or in parts of colon
 - May cause heartburn
 - Bleeding ulcers were thought to be caused by an increase in gastric acid. Now have discovered that a bacteria in the stomach can create a crater in the mucosa lining causing internal bleeding
 - Do not take aspirin or NSAIDS (i.e., Ibuprofen)
 - Take medication as prescribed
- b. **Constipation/impaction/obstruction**—(the longer feces stay in the colon the more water is absorbed and the harder the stool becomes)
 - Constipation
 - ✓ A hard stool that is difficult to pass. This is not related to frequency ("I'm constipated because I didn't have a bowel movement yesterday.")
 - ✓ Causes include low fiber diet, ignoring urge to pass a stool, decreased fluid intake, inactivity, certain drugs, aging, and certain medical conditions
 - ✓ Discourage use of routine laxatives-- glycerin suppositories and/or stool softeners preferred
 - Impaction/obstruction
 - ✓ Hard, dried feces that are packed into lower intestines (constipation that has gotten worse)
 - ✓ Symptoms are loss of appetite, abdominal cramping, leaking diarrhea, change in behavior
 - ✓ Impaction can lead to complete bowel obstruction
 - ✓ Seek medical attention, usually for oil retention enema, possible manual extraction, and even surgery with severe cases
 - Diarrhea
 - ✓ Causes include infections, irritating foods, parasites, etc.
 - ✓ Need to replace fluids to prevent dehydration

9. Immune system

Immune system is responsible for fighting diseases and foreign bodies. An immune system deficiency can leave the body open to infection. Causes include:

- a. Normal aging reduces immune system's efficiency
- b. Chemotherapy
- c. Steroid treatments (i.e., Prednisone)
- d. Recent transplant surgery (medications are prescribed to reduce resistance to foreign body)

e. HIV/AIDS

The number of older people with HIV/AIDS is on the rise. About 10% of all people diagnosed with AIDS in the United States, some 75,000 Americans are age 50 and older.

Therefore, it is important to remember to use Standard Precautions/ Infection Control measures while on the job.

It is also important that you do not pass an infection to people with a compromised immune system as this may lead to an infection they cannot fight.

PERSONAL ASSISTANT SERVICES AGING AND PHYSICAL DISABILITIES MODULE

SECTION VI - PHYSICAL DISABILITIES



VI. Physical Disabilities

- A. Therapeutic interventions
- **B.** Differences
- C. Spinal Cord Injuries (SCI)
 - 1. Autonomic dysreflexia
 - 2. Bowel care and bladder management
- D. Multiple Sclerosis (MS)
 - 1. Exacerbation
 - 2. Progressive
 - 3. Non-progressive



A. Therapeutic interventions

Depending on the person with a physical disability, therapeutic interventions will be unique depending on each individual. Therapeutic interventions can include range of motion (ROM), durable medical equipment (DME), Physical therapy (PT), occupational therapy (OT), speech therapy (ST), proper diet, etc. These interventions can be crucial to maintain or improve the health and welfare of a person with a physical disability.

B. Differences

As with any condition an individual with a disability is unique with unique strengths and challenges. Therefore it is imperative to check with the health care team to determine the interventions that are to be used with each person. For example, a person with multiple sclerosis may or may not be incontinent.

C. Spinal Cord Injuries (SCI)

The spinal cord is a long, rope-like cord about the width of your little finger that extends from the brain to the lower back where it fans out like a horse's tail; it is protected by bones called vertebrae. In between the vertebrae are discs which act as cushions. The spinal cord is the second most protected organ in your body, next to the brain.

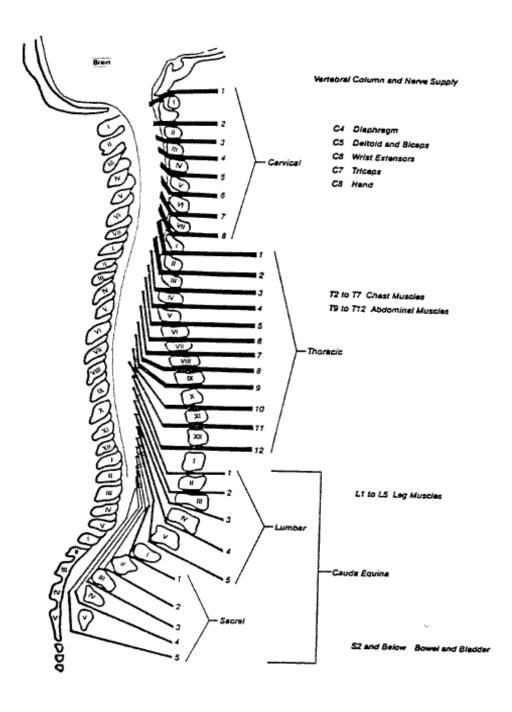
The spinal cord can be damaged easily. Some spinal cord injuries (SCI) are the result of something intrusive in the spine, for example, a gunshot wound. Another type of injury can be where nothing is intrusive into the column, but where pressure exists within the spinal column. An example would be a tumor inside the spinal column. Another type of injury can occur from actually breaking the vertebrae, which could then sever the cord.

Types of Injuries

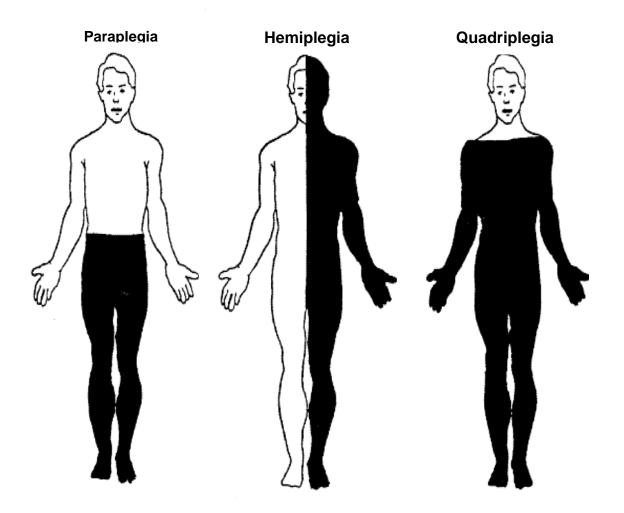
<u>Complete</u> – All the nerves at the level of injury are damaged. There will be no voluntary movement or sensation below the level of injury.

<u>Incomplete</u> – Partial damage to the nerves at the level of injury. There may be some movement and/or sensation.

The Vertebral Column



Types of Plegias -



This diagram illustrates the types of "plegias" and the areas of the human body that must be paralyzed in order to fit into a specific category of plegia. (Tetraplegia = three limbs affected.)

1. Autonomic Dysreflexia (Hyperreflexia):

Autonomic Dysreflexia (AD) is a condition, which causes high blood pressure as a result of a stimulus below the level of injury. This is an emergency situation, which can lead to a stroke!! It generally occurs in individuals who have an injury at T-6 or above.

What happens?

When a stimulus occurs in the non-injured body, blood vessels dilate and the blood pressure rises. Messages are sent from the brain to lower the blood pressure to keep the body in homeostasis (even state). In a person with a SCI, those messages cannot pass through the level of injury and the blood pressure rises uncontrolled. This rise in blood pressure will cause signs that the individual can see. These are the indicators that something is wrong.

Symptoms to look for are:

- a. Pounding headache.
- b. Profuse sweating (above the level of injury).
- c. Nasal congestion & pupil constriction.
- d. Goose bumps/chills.
- e. Slow heart rate (brain's response to high BP).
- f. Vision changes (seeing spots, blurry vision).
- g. Anxiety, apprehension.
- h. Flushing of skin (above level of injury).

What to do:

- a. Have the person immediately sit up or raise head to 90*. This will reduce the BP.
- b. Determine the cause.
- c. If you can't determine the cause, GET HELP!! Call or go to the hospital. Be aware that not all health providers will be familiar with AD. It is a good idea to carry an ID card, which explains it.

<u>Causes</u>

Causes of AD are varied. Basically it is any stimulus below the level of injury. The following are some of the causes:

- a. Full, distended or infected bladder. (Check the catheter tubing for blockage.)
- b. Blocked bowels.
- c. Pressure ulcers.
- d. Broken bones, severe cuts.
- e. Labor pains, menstrual cramps.
- f. Extreme temperatures, sunburns.
- g. Tight clothes.
- h. Stress.
- i. Ingrown toenail.

*This is not an exhaustive list. As stated earlier, it is basically any stimulus below the level of injury.

Psychological Adjustment

A person who has a SCI will go through a physical adjustment and usually also a psychological adjustment. There is no set time for the length of this process; nor is there a specific pattern as to how the person will handle it. Often you will see the individual experience the phases of the Grieving Process. Your role as the assistant is a vital one. Be as supportive as possible. Be honest with the person. It is good for the individual to look into the future, but remind them to focus on where they are now, both physically and emotionally.

Remember, people with SCI still have everything to offer. Using adaptive equipment, modifying the environment, etc., will assist the individual with SCI to utilize the abilities they have. To have your body's physical ability change often creates the idea that you

no longer have anything to offer. It's all a process of learning how to express yourself again.

CARRY A CARD!

Below is an example of a card you can cut out and carry in your wallet. Put your name in the space below "FOR AUTONOMIC DYSREFLEXIA." Let people know you have this card and use it with medical staff to instruct in emergency care.

It may save your life!

MEDICAL ALERT FOR AUTONOMIC DYSREFLEXIA

Is subject to the above syndrome. This is a serious medical problem that can occur in people with a spinal cord injury above the 6th thoracic level. The symptom of autonomic dysreflexia (AD) can be caused by many types of stimuli below the level of the spinal cord injury, but the most common emergency causes are: (1) full or spastic bladder or (2) bowel distention (usually from stool in the rectum). Severe AD is a medical emergency which if not properly treated can result in cerebral vascular hemorrhage (stroke).

Symptoms:

- 1. Pounding headache
- 2. Flushing of skin and sweating above the level of injury
- 3. Increased blood pressure (as high as 250/150), slow pulse
- 4. Apprehension/anxiety
- 5. Vision changes-blurring, spots before the eyes
- 6. "Goose bumps"

What To Do: (First Aid)

- 1. Place patient in a sitting position
- 2. Drain the bladder.
 - (a) If catheter is in place, check for kinking. If catheter is plugged, do not try to irrigate. Change foley using Lidocaine jelly for lubrication.
 - (b) If no catheter is present, insert a catheter using Lidocaine jelly for lubrication. Do not crede (push on) the bladder.
- 3. If emptying the bladder has not decreased the blood pressure and there is stool in the rectum, apply Lidocaine jelly to the anal sphincter and wait three minutes. Then, using a Lidocaine-lubricated gloved finger, gently remove stool from the rectum.

Medical Treatment:

- 1. If the AD episode is not resolving after the above measures, medical treatment is necessary. Ask the patient if he has his own supply of any of the AD medications. If not, transport patient to an emergency room as soon as possible.
- 2. If the AD episode is not resolving and/or the blood pressure reaches 160 systolic, give the patient Nifedipine 10 mg sublingual. Instruct patient to bite through the capsule and hold it beneath his tongue. May repeat Nifedipine dosage after 15 minutes if blood pressure has not responded.
- 3. Continue to look for causes of AD by checking the patient's entire body. Other causes include fractures, sores and tight clothing.
- 4. Alternative treatments (if Nifedipine is not available or does not work):
 - (a) Nitroglycerine ointment: 1 inch to upper chest or back. If no resolution in 15 minutes add additional 1 inch.
 - (b) Markedly elevated blood pressure not responding to the above measures should be treated with IV Apresoline (20 mg/1cc). Inject .5c SLOWLY. May repeat dosage after 15 seconds of no response.
- Blood pressure may be safely lowered to 90/60, which is typical of quadriplegics in the sitting position.
- After an episode of AD, it is not uncommon for a second episode or rebound to occur, so blood pressure should be checked every 30-60 minutes for the next 4-5 hours.

2. Bowel care and bladder management

The elimination of waste materials from the body is the function of the excretory system. The renal arteries carry the "dirty" blood into the kidneys where the wastes are filtered

out. Then, this waste liquid drains down the ureters into the bladder. The bladder is where the urine is stored until the sphincter muscle at the bottom sends a message to the brain saying, "I'm full, go to the restroom." At the time when you are actually draining your bladder, the urine is traveling down the uretha to the outside of the body.

Bowel training and control – Accident Free--

The goal for a bowel care program is to establish emptying the bowel at regular times, and prevent embarrassing accidental bowel movements. A bowel care program usually consists of inserting a suppository followed by digital stimulation "Dillie" routine. A bowel care program is usually established three times a week, but does vary from consumer to consumer. Please be aware—that with most agencies DSPs are not allowed to insert a suppository or perform digital stimulation. However, check with your supervisor to determine your job responsibilities. DSPs can perform the clean-up after a qualified person does the suppository and stimulation.

Bladder Control -

- a. Intermittent --catheter inserted every 2-4 hours directly into the bladder through the urethra allowing the bladder to drain.
- b. Indwelling catheter inserted into the bladder through the urethra and remains inside the bladder.
- c. Supra pubic catheter--Catheter is inserted just above the pubic bone through the abdomen into the bladder.
- d. External catheter
 - Male Condom, Texas
 - ✓ Change as needed. (Easier to change if penis is somewhat erect.)
 - ✓ Wash skin well to remove glue and old urine
 - ✓ Dry skin thoroughly
 - ✓ Clip hair that may be caught in glue or catheter

D. Multiple Sclerosis (MS)

It is a disease of the brain and spinal cord (central nervous system). Multiple Sclerosis (MS) interferes with the brain's ability to control such functions as seeing, walking, talking, etc. "Multiple" refers to many scattered areas of the brain and spinal cord. "Sclerosis" means the disease involves "sclerosed" or hardened tissue in the affected areas of the brain and spinal cord. As a result, body functions become uncontrolled, because messages don't get through correctly, or are sent to the wrong area.

Multiple Sclerosis is the most common central nervous system disease among young adults in the United States. The central nervous system acts like a switchboard, sending electrical messages along the nerves to various parts of the body. These messages control all our conscious and unconscious movements. Most healthy nerve fibers are insulated by a MYELIN SHEATH, a fatty substance that aids the flow of messages. In MS, the myelin breaks down and is replaced by sclera (scar tissue). This distorts or even blocks the flow of messages. Multiple Sclerosis is not a mental illness, contagious, preventable or curable.

What causes Multiple Sclerosis?

 Virus attack - MS might be caused by some slow-acting viruses, or might be a delayed reaction to a common virus.

- Immune reaction MS might involve an auto-immune reaction in which the body attacks its own tissues by mistake.
- Combination when viruses invade the body, they take over body cells. The body's
 defense system might become confused because some viruses take over parts of cells
 and it might attack both host cells and virus cells.

Who gets Multiple Sclerosis?

Since there is so much we don't know about MS, we can't predict who might experience it. However, there is a pattern in who is more likely to develop it:

- Young adults symptoms usually appear between ages 20 and 40.
- Women slightly more women than men develop MS.
- People in the temperate zones MS occurs more often between 40 degrees and 60 degrees north and south latitudes.
- People in areas with high standards of sanitation. Perhaps children in these areas are not exposed to some factor that would help build immunity to MS.

What are the symptoms of Multiple Sclerosis?

- Seeing double or uncontrolled eye movements.
- Partial or complete paralysis in any part of the body.
- Shaking of hands.
- Loss of bladder or bowel control.
- Staggering or loss of balance.
- Speech problems such as slurring.
- Weakness or unusual tiredness.
- Loss of coordination.
- Numbness or prickly feelings.
- Obvious dragging of feet.

1. Exacerbation

This term is quite often associated with MS, meaning the consumer is having a flare-up. Relapsing-remitting multiple sclerosis is a form of MS in which symptoms randomly flare up (relapse) and then improve or fade. This relapsing-remitting pattern emerges with the onset of the disease and may last for many years.

2. Progressive

Where the disease is progressive from the start, although damage to the central nervous system occurs at different rates in different people.

For more information contact: National Multiple Sclerosis Society

Arizona Chapter

627 S. 48th St. Ste. 110 Tempe, Arizona 85281

(480) 968-2488

VI. Physical Disabilities

- E. Amyotrophic lateral sclerosis (ALS)
- F. Muscular dystrophy (MD)
 - 1. Duchenne
 - 2. Facioscapulohumeral
 - 3. Limb-girdle
 - 4. Myotonic



E. Amyotrophic Lateral Sclerosis (ALS)

(also known as Lou Geherig's disease)

This disease is a progressive wasting away of certain nerve cells of the brain and spinal column called motor neurons. The motor neurons control the voluntary muscles, which are the muscles that allow movement. The cause for ALS is unknown. Symptoms of ALS in the beginning are weakness of one leg, one hand, the face, or the tongue.

ALS is a progressive, disabling disease. ALS affects walking, speaking, eating, swallowing, breathing, and other basic functions. These problems can lead to injury, illness, (pneumonia), and other complications. A person diagnosed with ALS will need to make decisions on treatment or lack of treatment as the ALS progresses. Treatment can include in the early stages use of a cane, shower chair, physical therapy, occupational therapy, speech therapy, medication as the disease progresses, assistance to breathe via a ventilator, and tube feeding.

F. Muscular Dystrophy (MD)

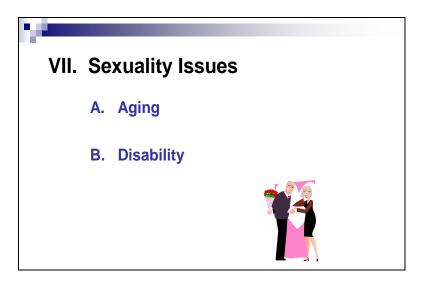
Muscular Dystrophy is an inherited disease. It is caused by a defect in genes that are important for healthy muscles. It is a group of similar diseases marked by dissipating and progressive weakness of the skeletal muscles (those that control body movement). It is progressive. Symptoms gradually get more severe as muscles dissipate. There is no cure and no way to arrest the disease process. Muscular Dystrophy (MD) is not contagious.

- 1. **Duchenne -** Develops early, between 2 6 years of age. Symptoms include: waddling or walking on toes, difficulty in running, protruding abdomen. Sex-linked: 50% more likely to occur in males, like hemophilia.
- 2. Facioscapulohumeral Usually becomes evident in teens (but may appear in infancy, childhood or middle age). Symptoms include: facial weakness always present (difficulty closing eyes and whistling, unlined face even in middle age). Difficulty raising arms, lifting objects, prominent shoulder blades. Dominant: gene arrears in nearly every generation and affects both sexes.
- **3. Limb-girdle** Usually becomes obvious in late childhood or early adolescence. Symptoms vary with body part affected: difficulty raising arms and lifting objects,

- drooping shoulder, waddling, frequent falls, difficulty rising from floor and climbing stairs. Recessive: appears only if both parents carry the gene; affects both sexes.
- **4. Myotonic** Appears in early adulthood, less often in adolescence. Symptoms include: stiffness in hands and feet, especially after chill, difficulty relaxing grip, and facial weakness. Dominant: affects both sexes.

PERSONAL ASSISTANT SERVICES AGING AND PHYSICAL DISABILITIES MODULE

SECTION VII - SEXUALITY ISSUES



VII. Sexuality Issues

One's sexuality involves the total sense of self as male or female, man or woman, as well as perceptions of what it is for others to be female or male. It includes attitudes about one's body and others' bodies. It expresses one's definition of gender identity. Sexuality is emotional, physical, cognitive, value-laden, and spiritual. Its dimensions are both personal and social. A distinction should be made at the outset between sex and sexuality. Sex refers to the physical act of making love, to genital expression. "Sex is in fact, only a small part of sexuality. Sexuality is an integrated, individualized, unique expression of "self."

<u>Sexuality is emotional</u> - The infant experiences what is later understood to be sexuality as it is fed and cuddled, in the sense of warmth or distance between bodies, in comfort or discomfort, at wetness or dryness of body, in pleasurable sensations of one's own body. In the early years the child experiences bodily pleasure and discovers sensuality. With the coming of puberty, boys and girls experience new awareness of their bodies, other persons, and related emotions. Throughout all of life, sexuality deals with one's feeling about self and others, pain and pleasure, distance and closeness, love and hate, physical touching or restraint.

<u>Sexuality is physical</u> - It involves touching, physical closeness, and genital sexual expression. It is expressive of the desire for human contact and satisfaction of the need for closeness, intimacy, and physical pleasure. All five senses are involved in one's sexuality; touch, smell, taste, visual and hearing.

<u>Sexuality is cognitive</u> - Mental attitudes, self-understanding, analysis of human experiences and relationships help express who and what persons are as sexual beings. One's understanding of genitals, coitus, nakedness, other and same-sex roles affect the body and its sexual expressions. Language is a key part of our sexuality both in naming parts, physical acts and our own experiences in communication with other persons.

<u>Sexuality is value-laden</u> - One's sense of the ought, the fitting, the possible, and the communal, reflect value systems and ethical structures. Words and concepts such as justice, love, norm, should, and should not, are ethical in character and are central to full understanding of sexuality. Values relate both to self-understanding, to expectations of others and of social structures. Values shape how and what persons communicate to one

another. One's values determine approaches to honesty, fidelity, promise-keeping, truth-telling, and the purposes of sexual expression.

<u>Sexuality is spiritual</u> - The sexual act involves mutual giving. The spirit of one person relates deeply to the spirit of another. One chooses to relate to another and to oneself. There is a voluntary surrender of self to another through which a larger unity is achieved without the abridgement of freedom. Elements of transcendence, commitment, being in touch with another and with oneself are involved in one's sexuality and relationships to others as sexual beings.

<u>Sexuality is personal</u> - Each person is a sexual being on her or his own terms. In that sense, one's sexuality is unique, one of a kind. Our sexuality belongs first and foremost to us. It is pleasure we want to give and get. It is vital physical expression of attachment s to other human beings. It is communication that is fun and playful, serious and passionate.

<u>Sexuality is social</u> - It involves couples or partners. It has familial and community caring contexts. Our sexuality has a bearing on the approach of such issues as war, economics, politics, or national priorities. It relates to such social policy questions such as rape laws, equality of women and men in matters of employment, guidelines for genetic research, and abortion. It affects cultural understandings of socialization as male and female, the role of pornography, and the meanings of marriage and community.

Excerpted from: Human Sexuality, A Preliminary Study, The United Church of Christ

A. Aging

Aging can have an impact on sexuality and sexual functioning. As with other organs the reproductive and sexual organs lose efficiency. Women usually begin to have vaginal dryness and oftentimes males have difficulty with erectile dysfunction. We don't discuss sexuality enough when considering the lives of older adults. It's easy to assume that aging brings dramatic changes and that sexuality is not a topic that concerns older adults to any great degree. Sometimes, however, events bring about a dramatic shift in awareness and understanding. The recent highly publicized events when the medication Viagra was released provided a vivid example of such an event.

(Refer to Aging and Human Sexuality Resource Guide –www.apa.org)

There is much information on the Internet regarding sexuality and aging, <u>sexuality and dementia</u>, <u>sexuality and Alzheimer's disease</u>, etc.

B. Disability

Disability can have an impact on sexuality and sexual functioning. Major types of disabilities and typical sexuality issues for those disabilities are described below. For detailed information about how a disability may affect sexual functioning consult a physician or other resource professionals.

<u>Amputation</u> does not affect sexual organ function unless the amputation involves the bowel or bladder. Amputations do not affect or lower the desire of sexual activity. Loss of a limb may cause depression or lower self-esteem but talking to a counselor, friend, or other professional can help eliminate these problems. Amputation will limit some of the physical

activities which may give your partner pleasure but open communication with you partner is the key to removing any stigma surrounding your amputation.

<u>Arthritis</u> does not affect sexual organ function but can impose limitations on physical activity. Pain and stiffness are the biggest factors that can interfere with an active sex life. Pain can dull the desire for sexual activity and limit the positions you can use in sexual acts. Fatigue from dealing with activities of daily living may also decrease your sexual desire. Stiffness can restrict movement and affect use of limbs. Experimentation with positions, the timing of medication and the timing of sexual activity can be worked out so that sexual activity is possible and pleasurable. In addition, the use of heat and warm-up exercises can be helpful.

Like amputation, arthritis can cause depression and lower self-esteem. Medications, too, can affect sexual desire. Other disabilities associated with arthritis can also cause problems for the person who wants to be active. Sjogren's Syndrome can alter vaginal lubrication, which means that the female with this disability may need to use lubricants. Behcet's Syndrome, Stevens-Johnson Syndrome, Reiter's Syndrome and granulamtous enteritis can produce oral and genital sores which can cause pain or alteration in appearance. If any of these problems present themselves, the person may wish to seek medical advice.

Counseling may also be appropriate. A positive note on arthritis and sexuality is that many people with arthritis report sexual activity actually relieves pain up to 8 hours after intercourse.

<u>Blindness</u> itself does not create any problems with sexual functioning. Rather, some of the disabilities which lead to blindness can cause other problems related to sexual functioning. For example, diabetes can cause blindness and also is known to cause impotence in some men. Congenital blindness will cause a woman to start her cycle earlier and she may have more irregularities. This happens because the pineal gland located in the brain regulates a woman's period and is affected by lack of light.

<u>Cerebral Palsy</u> does not cause loss of sexual functioning or loss of desire for sexual activity. Physical problems such as sensory loss and limited movements due to spasticity can be a problem. Medication may be helpful. Communication between partners is important when dealing with physical barriers. In many cases, people with cerebral palsy are socialized together and may develop relationships with each other. If this happens, education and counseling of all persons concerned (guardians need to be included if the partners have legal guardians) can be helpful to the two people desiring a sexual relationship. For the individual with cerebral palsy, the biggest obstacle to sexuality with a non-disabled person is the attitudinal barriers imposed by society. These barriers tend to socially isolate the person who has cerebral palsy, thus making communication and sexual activity more difficult.

<u>Deafness</u> creates no problem with sexual functioning. However, since the act of giving and receiving pleasure involves communication, the couple will need to work out a system for expressing needs and desires. One might also consider leaving a light on or using candles to enhance visual communication and to fully appreciate your partner's response.

<u>Diabetes</u> is not always thought of as a disability, yet it is currently the leading cause of permanent physical impairments in the United States today. Between 25 to 49 percent of males with diabetes develop impotence. There has been no correlation between diet,

duration of diabetes, or types of medication used for control over disability and the increase of impotence.

There also has been no demonstrated loss of interest in sexual activity among the diabetic population. Regardless of the reasons for the possibility of impotence, the person with diabetes may want to consider a penile prosthetic to increase sexual activity.

Epilepsy is usually thought of as a disorder occurring within the brain which causes some type of altered consciousness and which may be accompanied by uncontrollable physical movements or seizures. Men with temporal lobe epilepsy have experienced impotence and loss of sexual desire but not necessarily at the same time. Some medications used to control epileptic seizures may cause depression or drowsiness which, in-turn, may lower sexual desire; but these drugs do not cause loss of sexual functioning. Sexual activity does not cause seizures.

Activities sometimes associated with sexual activity such as excessive drinking, emotional tension, fatigue or lack of sleep and food may contribute to setting off seizure activity. Careful monitoring of activity, diet and rest should help you keep your epilepsy under control. Like cerebral palsy, epilepsy carries negative social stigmas, which are sometimes the biggest obstacle to enjoying sexual activity. Although major educational campaigns are underway, the person with epilepsy still must take the lead to make potential sexual partners understand that epilepsy does not interfere with sexual functioning, love, or marriage.

<u>Developmental Disabilities</u> do not affect sexual functioning or desires. Most of the problems experienced by people who are developmentally disabled relate to the attitudes of non-disabled members of the general public. In the case of legal guardianship, all persons involved may find it helpful to meet with counselors or other professionals. Education about human sexuality is important for mentally disabled persons and all others concerned with them. Education and communication will be necessary to work things out for both partners.

<u>Head Injury</u> can cause a variety of physical and emotional problems. These problems can be minor or major depending upon how much and what parts of the brain were damaged. No two head injuries are alike. Physically, there is no impairment in the sexual organs. The problems with sexual function stem from other physical issues such as loss of awareness of where your body is in space, loss of sense of rhythm and timing, loss of movement on one side of the body, or loss of sensation, which can limit sexual pleasure. Communication with the partner is the key to working out these physical issues.

However, if a person who has a head injury also experiences emotional disorders, then, depending upon the severity of these disorders, his or her ability to process information may be limited. The person may show poor judgment, irrational thinking and be very impulsive. The limbic system located in the brain stem is thought to control emotions and sexual urges. So, if the head injury includes damage to the limbic system, emotional problems and uncontrollable sexual urges may result. In some cases, education about the problem can help while in most instances, behavior modification programs and counseling are necessary.

<u>Spinal Cord Injury</u> does affect sexual functioning or desires. Since a spinal cord injury (SCI) affects virtually every system of the human body, many people who sustain SCI have serious concerns about how their injuries have affected their ability to participate in and

enjoy a sexual relationship. Sexual function in humans is controlled by parts of the central nervous system (CNS), particularly the brain and spinal cord. Interruptions to the CNS through injury to the spinal cord will therefore have some effect on sexual function. The extent to which sexual function is impaired, however, depends on a variety of factors including the level of injury, the severity of damage to the spinal cord, and whether the individual is male or female.

Female Sexual Function After SCI –A female's ability to engage in sexual activity is less likely to be affected by SCI by virtue of the way the female body is constructed. A woman is often able to have intercourse as easily after SCI as before, although additional lubrication may be needed to avoid chafing and to make the act of intercourse easier to initiate. Alternative positioning of one's body may have to be considered as well.

Male Sexual Function After SCI – For males, the situation of sexual functioning is a little more complicated. Some men are able to achieve erections quite easily, while others can achieve erections occasionally and some are unable to achieve erections at all after a SCI.

Sexual Sensation After SCI – As with other basic physiological functions after a SCI, sexual sensations can also be altered. Some of the nerves you once counted on to provide pleasurable feelings in sexual organs and other erotic areas of your body may no longer be working as they did before injury. Some people retain specific sexual sensations in the genital areas, while others notice they are diminished or absent. However, many others have reported heightened sensations in different parts of the body – the neck, earlobes, arms or other area of skin.

Many people who have sustained a SCI have indicated that their total enjoyment of the sexual experience after SCI is as good as, if not better than, their pre-injury sexual experiences. Necessity in many cases encourages them to concentrate on "holistic" sexual experiences rather that on genital-specific sex. Many individuals report that they can still achieve climax although frequently not in the same way as before their injury. Again, the best way to find out your own likes, dislikes, and needs is exploring them openly with a willing and loving partner.

SCI and sexuality was adapted from: SCI Network Fact Sheet 4, "Sexuality After SCI" http://spinalcordinjury.net/docs/scifact4.html

PERSONAL ASSISTANT SERVICES AGING AND PHYSICAL DISABILITIES MODULE

SECTION VIII - PSYCHOLOGICAL AND COGINITIVE CONDITIONS



VIII. Psychological and Cognitive Conditions

A. Anxiety

- 1. Signs and symptoms
- 2. Behavioral issues
- 3. Communication techniques
- 4. Treatment/Management



A. Anxiety

Anxiety disorders include:

Panic disorder Post-traumatic stress disorder (PTSD) Specific phobias Obsessive-compulsive disorder (OCD) Social phobia (or social anxiety disorder) Generalized anxiety disorder (GAD)

1. Signs and symptoms

Each anxiety disorder has different symptoms, but all the symptoms cluster around excessive, irrational fear and dread.

2. Behavioral issues

Depending on the issues involved people with anxiety disorders may not be able to cope with the stresses of everyday life. For example they may not want to venture outside of their homes or they may be afraid of germs to the point of having to wash their hands many times a day. Some people with anxiety disorders can become agitated and aggressive if taken out of their comfort zones. This is especially true for a person with dementia who has an anxiety disorder.

3. Communication techniques

Along with other therapeutic communication techniques you need to use a calm, reassuring approach. Listen with empathy (i.e., "I understand you are upset but you will be safe here.").

4. Treatment/Management

Treatment is aimed at the cause. If the person has a phobia, treatment may be focused on exposing the person to the thing that causes the phobia gradually (desensitization). Counseling may also help the person cope with stressors to reduce anxiety. Medications, including anti-anxiety agents, may also help. However, most anti-anxiety medications can be addictive.



VIII. Psychological and Cognitive Conditions

B. Depression

- 1. Signs and symptoms
- 2. Behavioral issues
- 3. Communication techniques
- 4. Treatment/Management



B. Depression

Major depression is the leading cause of disability in the U.S. and worldwide.

Older Americans are disproportionately likely to die by suicide. Among the highest rates (when categorized by gender and race) were white men age 85 and older: 59 deaths per 100,000 persons in 2000, more than five times the national U.S. rate of 10.6 per 100,000.

1. Signs and symptoms

- a. Persistent sad, anxious, or "empty" mood
- b. Feelings of guilt, hopelessness, worthlessness, pessimism (e.g., "I don't know if I can go on.")
- c. Loss of interest or pleasure in hobbies and activities that were once enjoyed

Some symptoms may be side effects of medication the older person is taking for a physical problem. They may also be caused by another condition or illness the person has such as heart disease, stroke, diabetes, cancer, and Parkinson's disease

Depression is **NOT** a normal part of aging

2. Behavioral issues (related to symptoms)

Statements about death and suicide
Reading material about death and suicide
Increased alcohol or prescription drug use
Failure to take care of self or follow medical orders
Stockpiling medications
Sudden interest in firearms
Social withdrawal or elaborate good-byes
Rush to complete or revise a will
Overt suicide threats

3. Communication techniques

Be supportive. It is important to let the person know that you are there to listen and spend time together doing things you both enjoy.

Be concrete and direct, though kind. For example, you could say something like, "You don't seem to be yourself these days. I've noticed that you have been sleeping more and not reading the paper like you used to enjoy doing. Are you OK?" You may find that the person will become defensive, tearful, or angry. However, it is important to keep in mind that your concern could be very helpful, even if it takes the person some time to come around. If you get a reaction like this, follow up at a later time. You might say, "I'm sorry you found what I asked you to be upsetting. I just wanted to help. Please let me know if I can help in any way."

Avoid being overly light-hearted or confrontational. Many people make the mistake of trying to get a depressed person to "snap out of it." Some do this by cracking lots of jokes and making light of the person's feelings. Other people will try to "get tough" with the depressed person, saying things like, "You don't have anything to be upset about," or "Think of all the people who are worse off than you." Such approaches are rarely helpful and may even backfire. The depressed person is likely to feel worse and may even become angry.

Ask questions. Depressed people often feel very alone and isolated. You might say, "I hope you won't find my questions rude..." or "Please let me know if I am asking something too personal..." Then ask! Providing the opportunity to talk can be a valuable gesture in helping a depressed person.

Ask about suicidal thoughts. Asking someone if he or she has thought about suicide will NOT increase the likelihood of the person doing so. In fact, people are often relieved to be able to talk about such scary thoughts. One way to do this is to paraphrase something that the person has just said, followed by a question about suicide. For example, you could say something like, "When you say that you feel like giving up on life, do you mean that you have been considering suicide?"

Try to get some help. Call your supervisor and report the situation so that an appropriate referral can be made. If the person is having suicidal thoughts, DO NOT LEAVE THE PERSON by themselves.

4. Treatment/Management

Research has shown that certain types of short-term psychotherapy are effective treatments for late-life depression. Combining psychotherapy with antidepressant medication, however, appears to provide maximum benefit. In one study, approximately 80 percent of older adults with depression recovered with combination treatment. The combination treatment was also found to be more effective than either treatment alone in reducing recurrences of depression.

Information adapted from the National Institute of Mental Health's Website: http://www.nimh.nih.gov/

PERSONAL ASSISTANT SERVICES AGING AND PHYSICAL DISABILITIES MODULE

SECTION IX - DEMENTIA SPECIFIC CARE

This part of the training is intended to introduce the student to Dementia-specific care. It is intended to be an overview of the topic.

However, the Alzheimer's Association, Desert Southwest Chapter, is developing a module by a committee of professionals in the field of dementia-related care that will provide in-depth training on providing care and treatment options.

Anyone who provides care for individuals with cognitive impairments and dementia is encouraged to attend the Cognitive Impairment/Dementia module training.



IX. Dementia-Specific Care

- A. Overview
 - 1. Types
 - a. Reversible
 - b. Irreversible
 - 2. Stages
- B. Communication strategies
 - 1. Verbal
 - 2. Nonverbal



A. Overview

What is Dementia?

- Group of symptoms which may accompany certain diseases or conditions
- Progressive, cognitive (thinking, reasoning, remembering) decline significant enough to impair daily activities

What are the Symptoms?

- Decline in memory, thinking, and reasoning
- Changes in personality, mood, and behavior
- Difficulties in language, visual recognition, and executing activities

1. Types of Dementia

- a. Reversible (Can be reversed with appropriate medical care)
 - Medical conditions
 - ✓ Dehydration
 - ✓ Infections
 - Chronic condition being out of control (i.e., thyroid problems)
 - Reaction to medication
 - ✓ Overmedication, mismanagement, withdrawal
 - Psychiatric causes
 - ✓ Depression, lack of sleep, stress
- b. Irreversible (Cannot be reversed with appropriate medical care)
 - Alzheimer's Disease
 - Vascular (Multi-infarct) Dementia
 - Lewy Body Dementia
 - · Pick's Disease

- Huntington's Disease
- Parkinson's Disease
- AIDS
- Creutzfeldt-Jakob Disease

Alzheimer's Disease: Scope of the Problem

- a. Nerve fibers twist into a tangle not allowing conduction of impulses
- b. Cause still being researched
- c. Affects more women than men
 - 10% of people 65-74
 - 19% of people 75-84
 - 47% of people >85
- d. Average life expectancy after diagnosis is 10 12 years
- e. 7 out of 10 persons with dementia live at home
- f. 80% of caregivers suffer from high levels of stress; 50% suffer from depression

2. Stages of Alzheimer's Disease

Early Stage

- Short term memory loss
- · Difficulty handling checkbook, finances, organization
- Poor judgment and personality changes

Mid-Stage

- Memory worsens
- Increased difficulty expressing oneself
- Difficulty using objects correctly (i.e., toothbrush, silverware)
- Disorientation to time and place
- Restlessness or pacing
- Behavior changes; Loss of impulse control
- Self-care abilities more impaired

Late Stage

- Limited/nonsense/no speech
- · Oriented only to self
- Incontinent bladder and bowel
- Needs maximum assistance walking/unable to walk/bedridden
- Requires total assistance for all ADLs

Terminal Stage

- Late stage criteria PLUS
 - ✓ Difficulty chewing/swallowing
 - ✓ Infection/recurrent fever in past 12 months
 - ✓ Pressure ulcers
 - ✓ Weight loss, weight loss, weight loss

B. Communication strategies

- Verbal
- 2. Nonverbal

stress is a major reason why service is requested

Note:

Caregiver

Trainer: Show Pieces of the Puzzle video

The two most important factors in working with the individual with dementia are your actions and reactions to the individual and his/her behavior.

Tips for Working with Difficult Behaviors Associated with Dementia

- 1. **Keep calm**. If the person is excited and you become excited, the situation will only get worse. Instead, maintain a calm voice and stature. Talk soothingly and reassuringly, using short, simple sentences.
- 2. **Take the person away from the present environment (<u>diversion</u>).** Perhaps there is something or someone causing the agitation. Try a different scene, such as a backyard patio, to see if the agitation decreases.
- 3. Talk and move slowly so that the person does not feel threatened. If the person is already feeling insecure or frightened, it will not help if someone else rushes in or speaks in a loud voice. Instead, stay relaxed and try not to upset the person further.
- 4. **Try soothing touch.** For certain people, a gentle arm around the shoulders, holding hands, or a gentle back scratch can be reassuring and soothing.
- 5. **Do not try to argue with the person**. Logical reasoning may seem like a good approach, but, because of the brain damage, it will not help a person with Dementia. Instead, try to "go with the flow" and let the person say whatever she/he wants to, even if you know it is not true.
- 6. **Respond to the emotions of the person**. Regardless of what caused the agitation, the person is upset. When talking with him/her, try to focus on what the person is feeling or what emotions they are displaying, instead of the actual words they are using.
- 7. **Try to <u>redirect</u> the person**. Changing the subject or the environment can often be helpful. Begin to talk soothingly about something you know the person enjoys, such as their family, or introduce an activity the person likes to do, such as draw pictures.
- 8. Always treat the person with respect and dignity. Never forget that the person is an adult, despite the behavior they are exhibiting. Again, recognize that it is the disease causing the behavior, not the person. Don't punish them or talk to them like a child.

These tips are adapted from "Alzheimer's Disease: Pieces of the Puzzle" produced by Arizona Long term Care Gerontology Center (now the Arizona Center on Aging) at the University of Arizona.

Also utilize the "Life Story":

The "Life Story" lists some of the unique aspects of that person's life. It can give caregivers valuable cues of what to talk about when trying to use distraction, and activities and music that the person should enjoy. If able, have the person help you complete a life story as part of reminiscing, or ask the family to assist in completing a "Life Story".

IX. Dementia-Specific Care

- C. Difficult behaviors
 - 1. Causes
 - 2. Types
 - 3. Tips
 - 4. Other
- D. Activities of daily living
 - 1. Personal hygiene
 - a. Bathing
 - b. Shampooing



C. Difficult behaviors

1. Causes

- a. Effects of Alzheimer's Disease on the brain
- b. Confusion
- c. Fatigue
- d. Pain
- e. Boredom
- f. Lack of routine
- g. Under/over stimulation
- h. The caregiver's approach and reaction to the behavior

2. Types

- a. Combativeness and aggression
- b. Wandering and rummaging
- c. Physical restlessness (pacing)
- d. "Sundowning" (becoming more confused/agitated in the late afternoon and evening)
- e. Inappropriate sexual behavior

3. Tips

The approach used by a caregiver can significantly impact problem behaviors with a person with Dementia. A caregiver can escalate a problem or they can calm the person by using the correct approach.

- a. Introduce yourself at each encounter
- b. Use touch as appropriate
- c. Try to determine the cause of the behavior (boredom, pain, anxiety, etc) and then try to reduce/eliminate the cause

- Boredom -- try a functionally specific activity
- Pain -- try the appropriate non-pharmacological treatment first
- Anxiety -- try reassurance and diversion
- d. Use the "Soft Approach"
 - Smile
 - Warm demeanor
 - Pleasant voice tones
 - Go slow
 - Talk in short, simple sentences
 - Avoid correcting/confrontation
 - Appeal to the emotion and let the person know you will keep him/her safe
 - Be flexible in getting tasks accomplished

4. Other

AD and sexuality --the following changes in sexual behavior, if exhibited, can be very upsetting for family members and the DSP:

- a. Bold behavior the person may forget marital status and begin to flirt with others including the DSP
- b. Unreasonable jealousy or paranoia
- c. Exposing or fondling self inappropriately
- d. Misinterpretations making sexual advances to another person (including the DSP) because he/she believes the person is the spouse

Note: This would make a good scenario for a role play exercise.

The DSP should try to determine if there is a cause for the behavior. If the person is fondling him/herself, the person may need to use the bathroom. If the cause cannot be corrected, gentle diversion usually works. However, if the DSP feels threatened or needs advice, the DSP should call his/her supervisor.

D. Activities of daily living

1. Personal hygiene

a. Bathing

Frequent Behaviors Seen During Bathing

- Fighting/resisting the caregiver
- Yelling/swearing/biting
- Crying/moaning

Why Behavior(s) Occur

- Person may be experiencing discomfort and/or loss of dignity
- The person is trying to say "NO"!

Trainer: Show Bathing Without a Battle video

Caregivers need to re-think the bathing situation and see the behaviors as "self-protective" rather than "combative" or "resistant"

Steps to Successful Bathing: Re-think the Bathing Experience

- Ask the family about the person's bathing preference prior to dementia
 - ✓ Shower vs. bath
 - ✓ Frequency and time of day
- Use bathing preferences and rituals that have been pre-established
- Keep in mind the goal is to create a comfortable and pleasurable experience for the person with dementia

Steps to Successful Bathing: **Approach Strategies**

- Always use the "soft approach"
- Don't ask the person if she wants a bath/shower if you are not willing to accept "no" for an answer!
- If the person refuses you, leave and come back again in a few minutes
- Use a variety of approach techniques
- Focus on getting "freshened up" or on a reason for the person to get clean

Bathing Steps: **Be Organized!**

- Have the room ready to go!
 - ✓ Shower room should be warm, well lit, with all the supplies ready to go
 - ✓ Position the person comfortably
 - ✓ Have enough bath blankets/towels to keep the person covered at all times

Bathing Steps: Helpful Tips

- Remember to keep the person covered at all times
 - ✓ Lift the blanket/towel as you bathe the person and then replace
- Begin bathing the least sensitive area first, the feet!
 - ✓ Begin with the feet/legs and move up from there, saving the perineal area and face until last
- Utilize distraction techniques
 - ✓ Play music or sing (person's preference—use the person's "Life Story")
 - ✓ Give the person something to hold
 - ✓ Give the person something to eat or drink
 - ✓ Give the person a piece of chocolate while washing the perineal area

b. Shampooing

- Save washing the hair until last OR separate it from the bath completely
 - ✓ Consider shampooing hair in a chair using washcloths and no-rinse soap
 - ✓ Make an appointment at the beauty shop/barber

Adapted from: Palliative Care for Advanced Dementia; Train the Trainer Program Alzheimer's Association: Desert Southwest Chapter



IX. Dementia-Specific Care

- 2. Activities
 - a. Importance
 - b. Functionally specific
 - c. Exercise
 - d. Other
- E. Pain Management Techniques
 - 1. Non-pharmacological
 - 2. Pharmacological
- F. Safety Concerns

2. Activities

a. Importance

Activities geared to the functional abilities of the person provide an opportunity for social interaction, encourages creative self-expression, increases feelings of achievement and enjoyment, and decreases agitation, boredom, and isolation.

b. **Functionally specific** gear activities to the functional abilities of the person. If the activity is too difficult, the person may become overwhelmed; if too easy, the person may become bored. Both can lead to problem behavior.

Possible activities:

- Give the person something meaningful to do such as folding towels
- Look at picture books and magazines and make a card or cut out pictures
- Play music of the person's preference or try singing old favorites
- TV programs only if the person shows interest (e.g. nature programs, musicals and "Lawrence Welk", old comedies like "I Love Lucy")
- Offer frequent snacks (sweets) and fluids
- Use lotion to give a 1-2 minute hand/foot massage consider adding an essential oil for aromatherapy
- Read a poem, prayer, or scripture verse

c. Exercise

- Accompany the restless person on a walk even if just looking at flowers on the patio
- Designate a safe area where the person can walk
- Take a person who uses a wheelchair for a walk

d. Other

E. Pain Management Techniques

A person with Dementia may not be able to tell a caregiver that he/she is in pain. Therefore, it is imperative that the caregiver be alert to changes in the person's behavior (even be the cause of problem behaviors) that might signal the person is in pain. Try to provide one of the following non-pharmacological approaches first:

1. Non-pharmacological

(not involving medication - caregiver can do these measures without a physician's order)

- a. Positioning/repositioning/walking
- b. Toileting
- c. Offer snacks/fluids
- d. Give a lotion massage
- e. Quiet time/reduce stimulation in environment
- f. Listen to music
- g. Body temp (person may be too hot or too cold so adjust clothing/thermostat)
- h. Use soothing touch and tone of voice

2. Pharmacological

If the non-pharmacological strategies do not work, report this to the family and your supervisor. The person's physician may be able to prescribe a medication that will be helpful. Just keep in mind that:

- a. A non-aspirin pain reliever such as Tylenol usually works well.
- b. Narcotics are usually not tolerated well in elderly individuals.
- c. Anxiety in an elderly person with Dementia is not always well-managed by antianxiety agents. Pills don't always work and some have serious side effects.

Adapted from: Palliative Care for Advanced Dementia; Train the Trainer Program Alzheimer's Association; Desert Southwest Chapter

F. Safety Concerns

Safety is the primary responsibility when caring for a person with Dementia. Make sure the usual fall-prevention measures are used (i.e., clear pathways, no scatter rugs, etc.). Refer to the accident prevention section of the Core Training.

Also, if the person with Dementia wanders, refer to the Safe Return® program through the local Alzheimer's Association Chapter. Once enrolled, if the person becomes lost, one call immediately activates a community support network to help reunite the lost person with his or her caregiver.

What would you do in these situations? What would you document and report?

A. You have been assigned to give a bath to Hazel who has Alzheimer's disease. Hazel is sitting at the kitchen table, drinking a cup of coffee. You say to Hazel, "Hazel, I am here to give you a shower. Why don't you finish your cup of coffee and I will start getting everything ready for you." Hazel says, "No, I just took a shower this morning and I don't need a shower."

What would you say and do? What would you document and report?

B. You are providing respite care from Noon until 6PM with Jean who has Alzheimer's disease. Jean's husband died last year and Jean came to live with her daughter. About 4PM Jean starts pacing and you find her at the locked front door trying to open it. When you ask Jean what is wrong, Jean states that she must go home now so that she can cook dinner for her husband. Jean is getting increasingly agitated.

What would you say and do? What would you document and report?

C. You are working with Ben who is in the late stages of Parkinson's disease and has Dementia. Ben requires a mechanical lift to get out of bed. You are midway through an eight-hour daytime shift.

What is an appropriate activity you can do with Ben?

D. You have been providing housekeeping and personal care assistance for Sarah who is 89 years old with severe arthritis. You notice that Sarah is pacing more, seems more agitated in the past few weeks, and is having problems with overdue notices on her utilities.

What action(s) would you take? What would you document and report?

PERSONAL ASSISTANT SERVICES AGING AND PHYSICAL DISABILITIES MODULE

SECTION X - END-OF-LIFE ISSUES

X. End-of-Life Issues

- A. Review of dying process
- **B.** Emotional Issues
- C. Responding to the changing care needs



A. Review of dying process

Death comes in its own time and in its own way Death is unique to each individual

One to three months prior to death

Withdrawal - This is the beginning of withdrawing from the outside world and focusing inward. With withdrawal you will see the person possibly taking more naps, staying in bed all day, and more time sleeping becomes the norm.

Food – We eat to live. When a body is preparing to die, it is perfectly natural that eating should stop. This is one of the hardest concepts for a family to accept. **It's okay not to eat.**

The person dying will notice a decrease in eating. Liquids are preferred to solids. Meats are the first to go, followed by vegetables and other hard-to-digest foods. Cravings will come and go.

One to two weeks prior to death

Disorientation – A person can't seem to keep their eyes open and is sleeping most of the time. They can, however, be awakened from sleep. Confusion can take place when talking to the person and the person may start talking about previous events and people who have already died. The focus is transition from this world to the next.

Physical changes that can occur are lower blood pressure, irregular pulse and breathing pattern.

One to two days, to hours prior to death

A burst of energy may be present.

Breathing patterns become slower and irregular, sometimes stopping for 10 to 45 sec.

Congestion may be audible.

Eyes may be open or semi-open and have a glassy haze.

Hands and feet become purplish and parts of the body become blotchy.

The person becomes non-responsive.

B. Emotional issues

1. Consumer and family

Individuals are unique in their display of emotions. Just because the person does not display what others think is "normal" does not mean that they are not grieving.

Some differences in grieving:

- Some people are quite vocal; some are quiet
- Some are accepting; some are in denial or shock
- Some people weep; some are very stoic (emotionless)
- Some people are angry; some may appear happy

DSP's need to be aware of the needs of the people they are assisting. If you think a consumer is not grieving in a healthy way, talk to your supervisor. He/she may be able to arrange agency or community resources.

2. DSP

Part of **healthy grieving** is to allow yourself to grieve—Not doing so can cause emotional and/or physical problems later on. Take care of yourself by:

Talking—to a social support system, to clergy or a counselor

Writing—journaling, even writing letters to the deceased person about things you wished you would have said

Reminiscing—remember the good times, plant a garden in the person's honor, support causes the person was involved in

Getting enough sleep, exercising, and eating healthy—keep your body healthy. Do no turn to alcohol or drugs to "numb the pain." This usually makes the situation worse. **Planning ahead**—Realize that anniversaries, holidays and special days will be difficult at first. Plan to spend time with a valued social support.

Don't be reluctant to ask for help—Help is out there; just ask.

As previously mentioned people grieve differently so allow yourself to grieve in your own way. You may need to talk to a valued social support. You may need to have some relaxation time. Try to be good to yourself and seek out the help that you need. Your supervisor may be very helpful in arranging agency or community resources to assist you.

C. Responding to changing care needs

The needs of the family

- 1. <u>To communicate about their problems, fears, and pain: Familes</u> are often overlooked in terms of their "disease" and can build resentment and guilt, as well as physical and emotional burnout if they are caring for a dying person. They need to have people ask how they are doing, and listen to their difficulties, without judging how they are coping, and without trying to "rescue" them.
- 2. To be told what the diagnosis and prognosis is: They need to know how their loved one is doing, when their physical condition is changing and all potential side effects of the therapy or disease process. They need to know what to expect as the person dies—the physical and mental changes that will take place, such as loss of appetite, skin color changes, labored or "rattled" breathing, lapses of consciousness or living in other levels of awareness. They also need to know when a person is actually dying—within a week, a few days or hours—and are often afraid to ask. If someone communicates this to them, they can say anything they have been holding back (even if the person is unconscious), call family members, or even bring the person home if this is their wish.
- 3. To make plans and set goals: Examples include where the person would like to die and how that can be arranged, making the person more comfortable and helping with care, (feeding, bathing, massage). Making arrangements on the use of life-prolonging equipment, funeral decisions, making wills and sharing financial information should all be handled as early as possible.
- **4.** To have time alone, when nothing is expected of them: Most family members will want to get out and do shopping or something more enjoyable, if only for a short time. This is possible if arrangements can be made for some kind of respite—maybe another family member, friend, or Hospice volunteer who can stay with the dying person for a few hours, a day, or for several days.
- 5. Children need to be aware of the dying process and have things explained to them honestly, simply, and directly: If possible, children should spend time with the dying person, to feel free to talk about death, to ask questions, and to have death treated as something which is a natural part of life. Family members can elicit the child's responses to death, and find ways of bringing out their feelings through play or drawings. Their mood swings—from anger to withdrawal to fear—should be honored and talked about. Children often have unspoken guilt that their actions or their secret wishes are responsible for the death, and it is valuable to bring this topic up. Events that take place when a person dies and the way the body is disposed of, should be explained on the child's level. Explain in familiar terms because often the child will not understand words like "cremation" or "embalming". You may need to go through this process a number of times before a full understanding is reached.
- 6. To understand the difference between accepting the coming death and wishing for the death: Sometimes acceptance is confused with wanting a person to die, and family members may be afraid to grieve in anticipation of the death. Crying can actually bring a family closer, and into a sense of trust that the death is all right and acceptable, even though it makes them sad.

- 7. Like the dying person, the family has a right to deny the full implications of the disease: However, when this denial prevents the family from speaking honestly, the result is isolation, both physical and emotional, for the dying person. Families should be encouraged to end this pretense, as it causes additional distress and loneliness for the dying person.
- 8. To spend time with the body after the death: This is especially important in the case of sudden death. While this is difficult for some, it helps members, especially children, become familiar with death, and experience firsthand that their loved one is gone. While a person is actually dying, and immediately after death, family members may want to say their last goodbyes, read prayers, sing songs that were special to the person, and encourage the person to let go of all that they may be hold onto in this world. Families who do spend time with the dead body, at home or in the hospital, often experience feeling of deep peace and joy during this time. Some families have been involved with assisting the mortuary with combing the hair or putting makeup on the loved one.

The needs of the survivor

- 1. <u>To talk about their loved one and express their felling to someone:</u> There is nothing you need to say or do, just being there and listening is often enough.
- 2. To have their feelings accepted by someone who won't judge them or try to "explain away" their guilt or anger: These feelings may include loneliness, fear, anger, sadness, apathy, numbness, guilt, despair, playfulness, feeling crazy, or overwhelmed. Sometimes they will feel like they are going crazy because they are not "in control" and do not understand their feelings. This is actually normal for such an intense loss.
- **To be reassured that it is okay to mourn, and for a considerable time:** Grief may be expressed through a need to get angry, to cry, or to escape for awhile. The intensity of their pain will diminish, but not for a long time.
- **4.** <u>Healing takes time:</u> it will not be over in a few weeks or months. The intense pain of their loss will reappear a few months after the death, at holidays, birthdays, and at the anniversary of the death. At the beginning, the experience of mourning is actually much like a serious illness that must be convalesced slowly. Feelings like loneliness or guilt may surface long after the survivor feels they have recovered.
- 5. Someone who will continue to be there for them; calling or coming by, even after being told they are not needed initially can be helpful. This continuity is important at first, for it establishes a thread of caring they can depend on for awhile. In time, trust builds, and they can ask for help when times get rough. The survivor will appreciate a person who shares themselves, their feelings and life. And who will go out with them occasionally.
- **6.** At first, allow the survivor to withdraw from the world: At this time, they may need the most help with daily living activities such as cooking, shopping, or childcare to allow them time to grieve. After some time has passed, they will want to take on

more responsibilities and gain full control over their lives again. Later, the need to withdraw will come up once in awhile, and they should be encouraged to allow this much-needed "retreat".

7. To understand various reactions are normal while grieving:

- a. Shortness of breath
- b. Poor concentration
- c. Irrational thoughts
- d. Feeling disoriented
- e. Dry mouth
- f. Preoccupation with images of the deceased
- g. Dizziness
- h. Skin temperature changes
- i. Nausea
- j. Loss of appetite
- k. Muscle aches
- I. Sighing
- m. Tiredness
- n. Racing heartbeat

8. To recognize and get past the barriers to expressing their grief:

- a. A fear of going crazy if they let it all out.
- b. Judging that they are just "feeling sorry for themselves".
- c. Guilt that they wished the person to die, or did not love them enough.
- d. Feeling that they should be over it by now (whether it has been weeks, months, or years since the death).
- e. Deciding they should be strong, and in control of themselves.
- f. Feeling distressed by the demand of too many well-meaning people around, or feeling isolated when they leave.
- g. Afraid to let children to see their grief.
- h. Worries about a job, financial security, or anger at the deceased person for being left with all those responsibilities.
- 9. Certain kinds of death bring out more intense reactions in grief: Sudden death, suicide, or the death of a child often results in greater shock, more guilt, anger, and feelings of despair or helplessness. Survivors fear they are really going crazy when these strong emotions overwhelm them. They need reassurance that someone will be there to make sure they won't go too far, and that it is best to talk out the thoughts that are most upsetting.
- 10. The expression of grief includes many feelings that seem abnormal: Only when certain feelings really interfere with a person's life for an unusually long period of time is there a problem that may require professional help. Some of these are: prolonged feelings of guilt; mourning that is repressed; extreme fear of the world; extreme identification with the deceased person's illness; continued denial of the death; or not being able to care of one's self or one's children. With high-grief deaths, even these reactions are normal for a time. Careful consideration should be given before suggesting professional help.
- 11. After the initial mourning has begun, the survivor can begin to set one or two short-range goals: They can learn new skills, resume old projects, or get involved in

a few social activities. It is also important to exercise and stay healthy during this time. Some of the resources for supports are: past interests or jobs, career guidance, community groups, volunteer work, colleges, skill training, re-entry programs, ministers, close family members, professional advisors, treating themselves to something new, or support groups for survivors, (Family Services, Hospice).

12. <u>Learn to assert themselves:</u> To re-enter the world, they must learn to communicate their needs and feelings, to ask for favors sometimes, and develop skills that will help them to live effectively in the world. Developing these qualities will balance the temporary feeling of helplessness and immobility that surfaces from time to time.

Suggestions for visiting with seriously or terminally ill individuals

A short visit conveys caring without taxing the person's limited energy. Sincerely ask how they are doing. Allow for their anger, fear, or disappointment. Avoid answers such as "I know how you feel." Few can really understand what another is feeling in such circumstances. Be careful when making statements about God's will. The experience of facing suffering, pain, and possible death often has a deep impact upon a person's relationship with God. Anger and questioning often precedes an acceptance of death as God's will.

Support the individual where they are emotionally. Comments such as "I feel so helpless to protect you from all that you are experiencing", or "I care so much about you, I wish I could change what is happening", are most helpful or a simple "I'm sorry".

Those who are dying are often expected to have brave comments and may be forced to pretend they are not frightened or in pain. An honest acceptance of them is a very needed and special gift.

Avoid trivia when faced with cataclysmic changes in one's life. It is hard to visit about things that have little meaning.

Allow for silence, work at being comfortable just being there. **Your presence can be more eloquent than words.**

Avoid advancing your life philosophies about life and death, fairness and unfairness. The ill individual needs to operate from their inner strength and philosophies. **Being a good listener will be a real gift to the ill person.**

Touch, hold a hand, or pat a shoulder, any touch will convey warmth and affection. If you take a gift, consider a balloon that conveys a message or a wall poster. They can do much to brighten up a sick room.

Remember the family. They may be under high stress. A phone call or note, or dropping off a meal will be greatly appreciated.

A seriously ill person is often avoided and may feel isolated and not important. Your caring and comfort will do much to ease their pain and loneliness.

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